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AUTHOR Kappel, Bruce
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ABSTRACT

The fourth of five volumes on the means by which Canadian communities can reduce the incidence of mental retardation, minimize existing impairment, and improve the quality of life of the mentally retarded, this booklet focuses on the prevention of mental handicap in adults and ways to accommodate and encourage community participation by the handicapped. The approach is based on a four-level prevention model which distinguishes between impairment, disability, handicap, and the feedback role of the environment. After an introduction, there are sections which deal with the following topics and examples: rights, freedoms, and responsibilities (equal opportunity and quality services); helping individuals with severe disabilities participate in community life; technological advances (communication and mobility aids); community homes; common features of successful community living arrangements; adult education for everyone (including the retarded); employment options (job sharing, jobs which often have a high turnover rate); living together, marriage, and parenthood; and getting older. (DB)

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MAKING A DIFFERENCE:

What communities can do to prevent mental handicap and promote lives of quality

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Volume IV: Respected and responsible citizens

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MAKING A DIFFERENCE
Respected and responsible citizens

Writer: Bruce Kappel

Series editor: Miria Ioannou

Prevention Project Resource Team
CHAIRPERSON
Robert Haslam, M.D., F.R.C.P.(C)
PROJECT COORDINATOR
Diane Richler

Graham Chance, F.R.C.P.(C)
Alan Etmanski
Marie Gallagher
Bernard Graney, Ph.D.
Ian MacLean
Martha Piper, Ph.D.
Kathryn Sullivan
Yves Talbot, M.D., F.R.C.P.(C)
Louise Vinet Lanteigne
Joseph Waters, Ed.D.
Colleen Wieck, Ph.D.

Consultant: Patricia Meyer

Designer: Barbara Bailey

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Downsview, Ontario M3J 1P3
CANADA

MAKING A DIFFERENCE:

What communities can do to prevent mental handicap and promote lives of quality

Volume IV: Respected and responsible citizens

National Institute on Mental Retardation

NOTE

The examples and stories in **Making a Difference** are about real people and real situations. In some cases the names of individuals have been changed to avoid unwanted attention to families and children. We do encourage you, however, to contact us at NIMR if you would like to receive more information on a specific example or story.

Dedication

Making a Difference is dedicated to Dr. Ronald J. Christie who spearheaded the involvement of the National Institute on Mental Retardation in the field of prevention. His death, in 1985, was a blow to the movement for persons with mental handicaps. Among his other accomplishments, Dr. Christie had also been an NIMR Associate, a former Vice-President of the Canadian Association for Community Living, a past President of the Metropolitan Toronto Association for the Mentally Retarded and a member of the American Association on Mental Deficiency.

Dr. Christie was a general practitioner in London, Ontario and a member of the Faculty of Medicine at the University of Western Ontario.

We believe that **Making a Difference** is a manifestation of Dr. Christie's hope that NIMR would take a leading role in not only helping to prevent mental handicaps, but also in promoting lives of quality for persons with mental handicaps.

Photographs

The photographs in Making a Difference are meant to illustrate certain situations and do not necessarily represent specific individuals or events. Photographs of specific persons, however, are acknowledged.

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PREFACE

In May, 1983, the Canadian Association for Community Living (formerly the Canadian Association for the Mentally Retarded) convened a group of approximately twenty people from across Canada in order to review developments in the field of prevention, to discuss the role of CACL and its member provincial and local associations in the field of prevention, to gain a better understanding of the role of the federal government in the field of prevention, and to develop a feasible action plan for future CACL involvement in this area. This symposium, made possible largely through a grant from the Health Promotion Directorate of Health and Welfare Canada, was the culmination of several years' work on the part of CACL. Since 1976, CACL had had a committee responsible for the area of prevention, and in 1979, when the CACL's Board of Directors conducted a major self-evaluation of the association's goals and structure, prevention was identified as one of the major directions to be undertaken by CACL.

The national symposium concluded an extensive two-and-a-half year consultation process with all regions of Canada through which a nationwide consensus had developed regarding the need for CACL to serve as a national coordinator and clearing house for information as well as a lobbyist at the federal level and provider of technical support. CACL would be supported in this role by its National Institute on Mental Retardation.

A significant contribution to the conceptualization of the problem was made at the symposium by Ron Draper of Health and Welfare Canada. Mr. Draper outlined a prevention strategy model developed by the World Health Organization (WHO) which he applied and adapted in his Directorate. Indeed, it was the presentation of this model which enabled the symposium to integrate CACL's interest in prevention within the context of the organization's overall concerns.

The WHO model suggests that prevention strategies can be implemented at four levels: the level of impairment, the level of disability, the level of handicap and the level of feedback.

The WHO model suggests that prevention strategies can be implemented at four levels: the level of impairment, the level of disability, the level of handicap and the level of feedback.

Impairment refers to a physiological or psychological loss or abnormality which would impair physical or mental function. Disability is a consequence of an impairment or a circumstance which prevents individuals from performing their social roles. Handicap refers to a disadvantage resulting from an impairment or disability that limits or prevents the fulfillment of social roles. The concept of feedback refers to situations where further impairments and disabilities are acquired as a result of handicapping circumstances.

This approach fit in very well with CACL's concerns which focus primarily on individuals living with a mental handicap. Consequently, the notion of working not only to prevent impairment from occurring but also to minimize existing impairment and promote lives of quality for individuals provided the impetus for **Making a Difference.**

Although in **Making a Difference** we do not use the WHO terminology in such a specific way as described above, the WHO model provides the framework for these publications.

Making a Difference is a series of five monographs which address how communities can reduce the incidence of impairments which cause mental retardation and also how they can reduce those disabilities and handicaps which are environmentally caused – often by where people live or work or go to school.

A heartfelt thank you is extended to the Prevention Project Resource Team who developed the framework and content of this series, and to the staff of the National Institute on Mental Retardation for producing the final documents.

Sincere appreciation is offered to Dr. Maureen Law, Associate Deputy Minister, Health and Welfare Canada and to Mr. Ron Draper, Director General, Health Promotion Directorate, Health and Welfare Canada, for their support and direction in the process which we hope will "make a difference" for thousands of Canadians.

Robert H.A. Haslam, M.D., F.R.C.P.(C)
Chairperson
Prevention Committee, CACL
and
Prevention Project Research Team, NIMR

INTRODUCTION

April 15, 1985 – a red letter day in Canada. Section 15 (the equality provisions) of the Charter of Rights and Freedoms came into effect –

> Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, religion, sex, age, or mental or physical disability.

April 15, 1985 – the day that all Canadians became equal citizens. The day that Canadians with mental handicaps became citizens.

Making a Difference deals with the issue of preventing mental handicap and promoting lives of quality. How then does citizenship relate to prevention? Quite simply, one of the major ways that people with a mental handicap are, in fact, "handicapped" is the way in which their fundamental rights and freedoms have been denied.

As we mentioned in the first three volumes of this series, helping children remain with their families and within their communities is essential in preventing further handicap and promoting lives of quality.

Preventing mental handicap, in the most positive sense, means ensuring that people with a mental handicap enjoy the same rights and freedoms as other Canadians, and are supported to meet their responsibilities as citizens.

Citizenship is a two-sided coin. It means having rights that are respected. It also means meeting one's responsibilities as a member of a community. The community might be a family, a neighbourhood, a place of work, a province, or a country.

Adults are expected to meet their responsibilities as citizens – to work with their fellow community members to build a strong community, to participate and contribute to the social and economic life of that community.

The World Health Organization (WHO) defines a number of social roles that a person is expected to play in order to function in his or her community. Three of these roles are –

- **Independence** – to be able to take care of and control one's life, body and circumstances.
- **Occupation** – to occupy one's time by working; furthering one's education; helping out family, friends and neighbours; and participating in recreation and leisure interests.
- **Integration** – to participate in and maintain social relationships in a household, a neighbourhood, the work place or in social and cultural activities.

The focus of Volume IV of **Making a Difference** is on preventing societal conditions which handicap adults and on promoting conditions which will help ensure that they live lives of quality. Most importantly, this means respecting the rights of adults as citizens of Canada, and ensuring that they are able to meet their responsibilities to the fullest extent possible.

The quality of life experienced and developed by adults with a mental handicap will always depend on the opportunities and supports they get when they are children. Earlier volumes in the **Making a Difference** series have suggested ways in which we, as communities, can take action. We must:

- ensure the well-being of babies and young children; and
- help children to live, learn and grow in their communities.

Regardless of the childhood experiences of adults, however, we must ensure that they are continually encouraged and supported to:

- develop their full and maximum potential as whole people;
- live in an atmosphere of affection;

- pursue an occupation of their choice, which contributes to the community and allows them to be recognized for their contribution;
- participate in the social and cultural life of the community;
- develop and sustain friendships and close relationships;
- be as self-reliant (independent) as possible, but also be mutually-reliant (interdependent) with their fellow citizens;
- exercise control over their lives, themselves and decisions which affect their lives; and
- feel a part of the human community, rather than separate from it, at all levels (a family or household, a neighbourhood, the world of work, social and cultural activities, and so on).

RIGHTS, FREEDOMS AND RESPONSIBILITIES

Canada's Charter of Rights and Freedoms has established the equality of citizens with a mental handicap in this country. We know, however, that this does not mean that people will automatically be able to exercise their rights or that the community will support them to do so. We must make sure that people know what their rights are and we must recognize that a community that respects and protects rights *prevents* societal conditions which handicap people, and *promotes* lives of quality.

The Canadian Charter of Rights and Freedoms assures the following:

Equal rights, worth, dignity, protection and benefit

- Every individual is equal before and under the law and has the right to equal protection and benefit of the law without discrimination.

The right to work, pay and the pursuit of a livelihood

- Every citizen of Canada...has the right...to pursue the gaining of a livelihood in any province.

Freedom of association

- Everyone has the fundamental freedom of association.

Life, liberty, development, security and support

- Everyone has the right not to be arbitrarily detained or imprisoned.
- Everyone has the right not to be subjected to any cruel and unusual treatment or punishment.

Equal opportunity and quality services

- ...Parliament and the legislatures, together with the Government of Canada and provincial governments, are committed to (a) promoting equal opportunities for the well-being of Canadians; ...and (c) providing essential public services of reasonable equality to all Canadians.

But what do these rights mean?

Very often, most of us take our basic rights and freedoms for granted. For example, we wouldn't think twice about having the right to choose the individuals with whom we live. Yet many adults with a mental handicap live in "residential services" (institutions, group homes and boarding homes) which give them no choice over the people with whom they live. Others would prefer to live with their families, but are unable because their families often do not receive the supports they require. Still others, would like to marry or share their lives with someone. This desire is often frowned upon and generally discouraged since individuals with a mental handicap are not com-

monly seen as having a right to intimate relationships.

We also expect our education systems to prepare our young people for adult life by providing them with an appropriate education, the skills for an occupation and a lively sense of their rights and responsibilities. This is "equal benefit of the law."

Many students with a mental handicap, however, are not encouraged to prepare for adult life and are not expected to learn to work. This expectation runs counter to what we know is possible. It has been demonstrated time and again that adults with severe and multiple handicaps are capable not only of working, but of working for wages.

For most of us, "The right to life, liberty and security of the person" means that our lives are not threatened, our liberty is not restricted, nor are our bodies invaded. Yet across Canada, women who have been labelled "severely mentally retarded" have been routinely sterilized without their permission. Men and women have been consistently institutionalized because supports were not in place to allow them liberty in the community. People have been denied life-saving and life-enhancing medical treatment because they were deemed "not worth it" because of their mental handicap.

Canadians also have a right to "essential public services of reasonable equality." Unfortunately, right across Canada, many communities are without sufficient services to respond to the needs of citizens with a mental handicap.

The right not to be subjected to any cruel and unusual treatment or punishment may seem to many Canadians to pertain to countries that are the target of protests by such organizations as Amnesty International. The fact is that many adults in Canada who have been institutionalized become anxious, depressed, withdrawn, or aggressive, precisely because they are inappropriately considered unable to live in the community. Deprived of affection and an education, people are being emotionally injured and subjected to cruel and unusual treatment.

The preceding examples of how rights are denied are just some of the examples of the *barriers* and lack of opportunities which stand in the way of adults with a mental handicap performing essential roles in our communities. As such, they are examples of what must be the object of *prevention strategies.*

Despite the fact that the rights of persons with a mental handicap are often denied, there are many indications that they are now demanding much more participation in decisions that have traditionally been made by others.

There have been changes in the attitude of some governments and communities, and of human service agencies in general.

Changes are being seen in all sorts of places:

- **in the courts of our country:** People with handicaps are demanding a say in making the decisions which affect their lives and their friends are helping to protect them from actions over which they have not had a say. For example, Justin Clark, who had been institutionalized for many years, was finally supported to go to court and have himself declared "mentally competent" so that he could begin living a more independent life in the community;
  - "Eve" (a pseudonym) is a woman whose right not to be sterilized is being supported in the Supreme Court by the Canadian Association for Community Living and consumer representatives of the association;
  - People with handicaps in the Ongwanada Hospital in Kingston won a case against a doctor who had instructed her medical students to perform rectal examinations on the residents without their consent or their families' consent.
- **in the living rooms of families:** Adults are discussing their hopes, aspirations and freedoms with their parents over such mundane issues as curfews and such major issues as getting a job, learning to ride the bus, and getting married. Professionals are sitting down with parents and adults in their homes to discuss what *they* think they need for a quality future.
- **in the board room of agencies:** People with a mental handicap are taking their seats as members of boards of directors. Agencies are beginning to chart the future based on the strengths and needs of individuals. Boards are becoming more aware of the wider group of people requiring support in their communities rather than only those currently receiving service.
- **in the conference rooms of professionals:** The presence of adults with handicaps and their families is increasingly required in the process of planning services. In some cases the individual and the family are seen as the core decision-making group, with professionals being invited to provide their expertise, not their control.
- **in the meeting rooms of People First organizations:** Adults with a mental handicap are forming their own organizations for self-advocacy and action.

Changes are also reflected in all sorts of laws and processes –

- **the Charter of Rights and Freedoms:** People with mental handicaps are guaranteed the right to vote, and the right to due process in decisions affecting their lives.
- **Education laws:** Children and families are guaranteed an opportunity to review the child's placement or educational plan.
- **Legislation on individual planning:** For example, in Quebec, people with a mental handicap and their families are guaranteed the right to request the Office of People with Handicaps in Quebec (OPHQ) to prepare an individual service plan in order to facilitate the individual's educational, vocational and social integration; in many child welfare acts it is required that individual service plans be developed for children.
- **Deinstitutionalization plans of provincial governments:** In Ontario, Quebec, British Columbia and New Brunswick, for example, the active participation of the individual and the family in the development of plans for community living for individuals leaving institutions is now required.
- **Guardianship laws:** It is increasingly recognized that adults should not have all their rights to make decisions taken away simply because they may have trouble making good decisions in one area of life (see, for instance, the Dependent Adults Act in Alberta).

You can make a difference in the amount of control people with handicaps and their families have over decisions by using some of the following suggestions.

Taking action

- As a parent, insist that professionals meet with you to discuss precisely what you and your son or daughter needs so that the supports and services do not get in the way or prevent building a life of quality. Join with other parents and their sons and daughters to insist that you be present when decisions are made, that information is provided to you, and that your views are taken seriously. For example, the Woodlands Parents Group in British Columbia first began to monitor what was happening to their sons and daughters at Woodlands Institution in the 1970s. They were instrumental in developing a community-based response to the needs of their sons and daughters as well as in actually moving people out of the institution.
- As a parent or a professional, listen to and take seriously the hopes, aspirations, and fears of people with a mental handicap. Give them an opportunity to learn what the world is all about. Act on their hopes and help everyone involved to learn from experience. For instance, one agency which supports people to find work learned from one young man that he wanted to be a policeman. There was little chance that this could be possible. What was possible, and in fact happened, was that the young man was assisted to find a job in a police station.
- Whoever you are – parent, professional, policy maker or handicapped person – insist that any attempts to move people from institutions to community settings be based on an individual planning process – a process by which supports are designed to respond to the individual and continue to respond to the individual as his or her strengths and needs change. The Community Living Society in Vancouver insists that individuals are the focus on the planning process which is based on sound values and principles. Planning is not just another way to fit people into slots.
- As a member of a political party, insist that election campaigns address people with mental handicaps as a group of people who have the right to vote; to hear about the issues; and to be heard. Help develop a "voters' workshop" for any citizen who is new to the voting process (young people, new citizens, citizens with handicaps) to have the opportunity to learn what voting is all about and how it is done.
- As a professional or board member, insist that your agency respond to the strengths and needs of individuals. Design programs that fit people, rather than forcing people to fit into programs. Respect the rights of handicapped people and their families to be actively *and* decisively involved in decisions which affect their lives. For example, don't just find a person to fill a bed, but find a suitable living arrangement for a person.
- As a manager or board member, welcome people with mental handicaps into decision making positions, and support them to be informed and active participants.
- As a parent, professional or person with a handicap, become intimately familiar with the rights of people with handicaps and the specific requirements of legislation for the involvement of individuals and families in decision making. Ensure that you are fully involved, and involve individuals and their families. Insist that agencies respect the rights of people to be fully in-

volved. If you see or know of any situation which denies people their rights to due process, inform the authorities. Reports of the abuse of residents of the Hôpital Rivière-des-Prairies in Montreal spurred on a parents' group to demand a full-scale government enquiry while keeping the media fully informed of the situation.

- As a parent or advocate, learn about the inexpensive legal or para-legal ways of redress that are available such as inquests, human rights commissions and the ombudsman.
- Whoever you are, insist that the participation of individuals and families in decision making is not token participation. Here are some signs of token participation:
  - □ scheduling professional meetings (case conferences, planning meetings), then informing parents and holding the meetings even if parents and the individual cannot attend;
  - □ planning meetings which involve parents and the individual only after professionals have met and discussed the position they will take;
  - □ sending permission forms to parents and individuals asking for blanket permission, rather than for permission to undertake a specific treatment or program;
  - □ setting agency guidelines for including parents and individuals in meetings, rather than general policy statements requiring their participation;
  - □ having case managers (people who are responsible for coordinating the development of plans and coordinating their implementation) assigned responsibility for so many people that, at best, they can visit them only once a year so that any claims for real individual coordination are unfounded;
  - □ being part of the planning process, but only being able to choose among existing alternatives (for example, one or two group homes or a sheltered workshop) rather than having alternatives created in response to the individual's needs;
  - □ being part of an individual planning process but not getting a copy of the decisions, not being asked to sign a copy of decisions acknowledging that those were the decisions made, not being able to take a consensus that those were the decisions made, and not being told how the implementation of those decisions will be monitored.
- Insist that the agency where you work as staff or a volunteer or where you obtain services has a clear statement of values and principles on which decisions are made and action taken; a clear statement of the ways that individuals and families can be actively and decisively involved in decision making; and a clear statement of the ways that individuals and families can appeal decisions with which they do not agree.
- As a citizen, encourage, support and stand beside individuals and families who go to court to fight for decisions which uphold people's rights.
- As a friend, encourage individuals with mental handicaps who are forming organizations like People First.
- When you are given a choice of options, (whether they be in terms of a place to live, learn or work) demand the opportunity to see, visit, hear about, or read about how those options actually work for people like the individual about whom and with whom decisions are being made. Take a "show me" attitude, and demand the right to make informed decisions.

▶ PARTICIPATION

Even when the rights and freedoms of individuals are respected and they are deemed equal to other citizens in the eyes of the law, there is still a long way to go before they become full, contributing members of the community.

True participation in the community means getting out and about, being active, feeling a part of things, feeling like you belong with your family, your classmates, your colleagues.

It also means that your life has many dimensions and is rich in experiences.

Most of us get a sense of who we really are, what we can really do and what others think of us from the different reactions of the people we spend time with in different settings. We are all more than the sum of our parts, but those different parts sure mean a lot in terms of who we are – parents, spouses, neighbours, relatives, cookers of meals, doers of laundry, negotiators of contracts, press operators, union members, second basemen, relief goalies, Civitan members, ushers at church, part-time volunteer parents at the day care centre, fans of Thursday night T.V., bridge players, and on-again-off-again campers.

The problem for many adults with a mental handicap is that life often has very few dimensions, very little depth or breadth. For some, diversity means watching different soap operas on T.V. For some, being part of things means riding the special bus from home to the special day program and going to the special dance once a month or the bowling alley with other special bowlers.

And for some, being special means never leaving the four walls of a ward, never satisfying a "Big Mac attack" unless there are three other people who have the same attack at the same time, and there is enough staff available to plan an "outing."

For many, being a part of things means being involved and having choices and people around who can help you act on those choices.

- instead of only having someone stay with you on Saturday morning while parents do the grocery shopping, learning and doing the grocery shopping with them;
- instead of going to the special adult camp, going camping in the local provincial park with friends (some of whom might be paid to go with you);
- instead of going to "handicapped bowling," joining your sister's bowling league and trusting the people you know to give you a chance;
- instead of hanging around the living room watching T.V, hanging around at the local doughnut shop, or going to the pub with friends;
- instead of learning to hook rugs in the sheltered workshop, taking a night course at the local high school with your neighbours, or getting a job during the day;
- instead of only visiting with your parents' friends for the evening, going to the local library and spending time with a tutor learning to read and write;
- instead of wondering about what to do on the weekend, learning to sail with instructors or friends;
- instead of learning woodworking at the sheltered workshop, getting Uncle Harry to show you how.

These sorts of things are going on across Canada. We are recognizing that things can happen for people with mental handicaps in the same ways and with the same people as they do for so-called "regular" folks. What it takes is often common sense and the direction of the extra resources required for some people to participate in regular community activities.

Jacqueline Boucher is in her fifties. She lives with a family in rural New Brunswick. She's like an aunt to the kids. She doesn't work outside the house, but she sure does inside. The pattern of her day and week is much like that of any other woman who works in the home in her part of the world. The reason – she and the homemaker in the house do most things together, the shopping, visiting neighbours, the chores, going to church.*

Catherine Schaefer is a young woman from Winnipeg with, what many would consider, very challenging needs. She uses a wheelchair, communicates non-verbally and needs assistance for almost all her daily needs. A few summers ago, her family was planning a vacation which, unfortunately, could not include Catherine.

As was customary, Catherine was to spend this time in an institution's "respite" program. Fortunately for Catherine, however, a group of friends which included two other individuals with needs similar to hers, invited her to go camping in the Rockies.

In all, eight people, in a van and a car drove to Calgary, Banff and Regina. A member of the group recalls: "...a picnic at Coral Creek with grapes and a red and white checked tablecloth; a spaghetti dinner with homemade sauce and two bottles of wine; the gondola ride at Sulphur Mountain; shopping for souvenirs for ourselves and our families – these are the memories from the Rockies." (Lutfiyya, 1984).

Twenty-four-year-old Donna Marchese lives with her parents and two brothers. Until she was 18, she went to a special school. She can write her name, address and telephone number. After school, she worked in a factory until she injured*

**pseudonym*

her back. Now she works at a training centre but is unhappy about it.

Articulate and friendly with a good sense of humour, Donna is very excited about joining a literacy program and getting a tutor. She has a long list of things she wants to learn: how to read newspapers and stories, improve her handwriting, write letters, use a dictionary, use public transit and draw.

Norman Maniago lived most of his life in Woodlands, an institution in British Columbia. He spent most of his time in bed because he had trouble walking. He never went to school. He does not talk. People fed him, took him to the bathroom, and sometimes restrained him while he slept. His parents joined together with other parents and brought Norman home to Vancouver. He now lives in a three bedroom bungalow with two other young men. He went to the local high school for awhile. Norman now works in a greenhouse. He is very involved with his family and has made new friends.

Those friends take Norman to the beach. His brother takes him for motorcycle rides. Since leaving the institution, he wears glasses (for safety reasons, he didn't when he was at Woodlands) - he really enjoys the view from the back of that motorcycle.

Helping individuals with very challenging needs to participate

Very often, people are not permitted to leave restricted environments because they are considered to have either severe behaviour problems or very demanding physical or medical needs. There have been significant advances made in helping individuals in these kinds of circumstances so that they are able to function quite well in integrated community settings.

Programs have been developed (Donnellan, LaVigna, Zambito, and Thvedt 1985) whereby individuals with very challenging behaviour problems are aided to overcome these with nonaversive, intensive intervention methods.

Individuals whose needs are much more physical can also be supported to live successfully in the community. Work done by such physical management experts as Lee Ellen Philips and Karen Green McGowan has shown that severe physical problems can result from incorrect seating and positioning and can, in fact, worsen a person's mental handicap. According to Philips, "if a person is correctly seated, then new opportunities for other functional activities arise, daily activities are made easier and some deformation patterns are actually decreased."

As far as people requiring large amounts of medical care are concerned, it is also possible for them to receive the services of nurses or homemakers in their homes as needed, to train the people with whom they live to provide the care that is needed.

Denise Makem had been living in a nursing home for many years. When plans were made for her to move to a home in the community, the staff was very apprehensive. Denise had severe disorders, was very withdrawn, and had spent most of her life lying in bed or on a mat on the floor. Her "fragility" was such that if there were many changes in her life such as a move from one part of the home to another, she would seizure to the point of requiring hospitalization.*

When it came time to move to the community, Denise went to a house where nurses were available at all times, where oxygen and suction apparatus was provided and where direct care staff were trained in positioning and seating techniques.

By the end of the first year, Denise's life was completely changed. Not only had seizures decreased in number and in frequency, but her tolerance for change had grown beyond everyone's expectations. Denise was using a wheelchair to explore the kitchen of her new home, had her hair tinted and permed and took

**pseudonym*

the train to see her mother in a nearby city. She even rode the bumper cars at a local amusement park!

Technological advances

Just like in every other aspect of modern life, technology is playing a growing role in the lives of individuals with mental and physical handicaps.

We now have the capability to assist people, especially those with the most challenging needs, to have greater control over their environment, to be more independent and participate more easily in community life.

Developments in microcomputer technology in such areas as communication devices, mobility aids, environmental control systems and computer assisted instruction all have the potential to vastly improve the lives of people with handicaps.

By puffing and sipping on a straw, I can adjust the light in my living room to suit my own convenience. I can tune in a concert on the radio or dial a TV special. I am able to summon assistance, when I feel it is needed, by means of an emergency signal light. I can involve myself in typing projects. I can answer incoming calls, and make outgoing calls with the help of the operator. Most important of all, I can engage in my chosen activity whenever I wish and without having someone present to help me. (Pfrommer, 1975; cited in Developmental Disabilities Program).

A PLACE TO LIVE

As we have said earlier in this volume, most of us take for granted our right to choose where and with whom we live. Given the choice, many Canadians prefer to own their homes, either individually or in some kind of co-operative arrangement. Most of us also want to make our homes our own by having our own things arranged in our own way and by being assured that we can live there as long as we pay the rent or the mortgage.

Unfortunately, many adults with a mental handicap do not have these opportunities. Even if they are living in the midst of a community, if they live in group residences, they often have little control over their environment or their lives. Their "home life" usually resembles this:

- they live with groups of people who also need to learn how to be more self-reliant at home;
- often the schedule of the household is determined by the needs of staff and the management of large numbers of people, rather than the preferences of the individuals;
- people who have trouble orienting themselves, getting themselves around, or staying out of trouble in the community are often denied the opportunity to leave their residences because staff are unable to accompany them; they have no friends who could accompany them;
- many individuals are medicated to control their behaviours, and as a result, are cut off from experiencing the world in a full sense, and denied opportunities and expectations which will encourage appropriate behaviour;
- little is expected of them in terms of the life of the household, so much is done for the individual, rather than by the individuals.

These are the realities for tens of thousands of adults with mental handicaps in Canada. On the other hand, most adults live at home with their families, and to a lesser extent, on their own in the community. For many, this is the situation of choice - they and their parents want to live

together. However, for many, this is the choice of necessity – there are not acceptable alternatives to living at home with their parents.

A recent study done in Manitoba (Fishbach & Hull, 1982) but whose results are applicable nationally, showed that people with a mental handicap were living in the following kinds of places:

Independent living	3.2%
Family or relative	54.4%
Foster home	9.8%
Other residences	9.0%
Community group homes	3.8%
Institution	19.8%

Of those individuals considered to have "moderate" or "severe/profound" handicaps, 22.8 percent ("moderate") and 58.0 percent ("severe/profound") were living in institutions. An additional 10 percent of each group were living in community group homes or other residences.

People can live in homes – we can help them to do so

Right across North America, communities are accepting responsibility for helping adults with a mental handicap to live, grow and develop, assume responsibilities and develop relationships in places we would all recognize as homes, not "residences."

In the past, the only alternative to living with one's family was an institution. Then, community residences were developed as an alternative for those wishing to leave home, and for those who were returned to the community.

Today, our ideas are changing. There have been dramatic changes in what we can do.

In the early 1980s, over 150 children and adults were living in an institution in northwest Quebec. By 1983, just over 100 of those individuals had moved into the community and into households of families in the region, or into their own apartments with a non-handicapped person, or back with their natural families. The natural and host families received advice and assistance from the staff of the agency who visited them on a regular basis.

In an evaluation of this effort to develop supportive homes for these individuals, the following observations were made:

Most people in the family residences live in a family setting with, at most, one other handicapped person... Many have numerous opportunities to develop relationships with non-handicapped people in the family or neighbourhood. Host families regularly told us that individuals have grown and developed considerably since leaving the institution.

The current community living situations are a vast improvement over what individuals would have experienced in the institution. The family residences are an excellent example of the positive impact that results from living with caring and decent people in nice homes in normal neighbourhoods... (Kappel, Burke, Cawthorpe, and Wray, 1983).

In 1983, Martin Bleecker lived in an institution in Manitoba. At various times he had been labelled as violent, destructive, rebellious, withdrawn self-abusive, sexually aberrant, antisocial, eccentric, and psychologically disturbed. He had been diagnosed as "severely mentally retarded," "mildly mentally retarded," "trainable mentally retarded," and as having "acute psychosis." He has a hearing loss, probably severe in one ear and some loss in the other ear.*

According to Martin's brother, his life in the institution was unacceptable, because he was "stagnating, not living a normal life... He was doped up, locked up, had no friends or privileges. He lacked a sense of belonging..."

**pseudonym*

In 1984, Martin was living in a townhouse in suburban Winnipeg. He shared his house with his brother and another man. The house is part of the Prairie Housing Co-operative. Close by are two other houses which are part of the Co-op. Two families live in those houses and are actively involved in Martin Bleecker's life.

According to his brother,

> *The Co-op means an opportunity for Martin to live a normal life in his own home. With freedom. With his own friends. He can go to the fridge and get a snack and take his bath by himself, not a communal bath. He is not pressured by routines... His walking and sitting posture have changed. He uses his muscles. He is more active. He walks beside people, not behind them...He has a chance to go to dances. He is meeting women.*

The world changes. Martin Bleecker's brother got married and moved down the street. A couple moved in with Martin to share their life with him.

Since moving into his new home, Martin's medications have been reduced significantly and he has learned a great deal –

- *to do dishes, vacuum and make the bed*
- *to brush his teeth and go to the bathroom*
- *to relax and interact with others without hitting them or himself*
- *to not pat women, but offer them a handshake*
- *to speak more and initiate conversations*
- *to use the fridge properly rather than raiding it all the time*
- *to dress himself*
- *not to masturbate in public*
- *to go to a restaurant*

Martin Bleecker is a young man who has presented significant challenges to services attempting to meet his needs. Most of the people who are intimately involved in Martin's day-to-day life are his friends. They are not paid staff. Many are fellow members of the Prairie Housing Co-operative of which Martin is a member and which assisted him to get his new home. There are eight other people with handicaps and 45 non-handicapped people who live in the 18 houses which comprise the co-operative and which are located in five different neighbourhoods throughout Winnipeg. (Kappel, 1985).

In 1983, 22 adults were living in a special care home in rural New Brunswick. When a group of local citizens were made aware of the deplorable circumstances in that home, they developed and got approval for a plan to close the home and develop more suitable arrangements in the community.

Raymond Langlois lived in the special care home for two years and had also lived in a much larger institution for 14 years. In 1983, Raymond spoke a few words, but was also very curious and friendly, walked reasonably well, could do a number of things for himself around the house, and followed directions well. In 1983, Raymond was spending the vast majority of his time alone in a barren room with only a plywood chair which resembled a throne. The door was locked with a chain. Raymond was occasionally tied to the chair.*

In 1984 he moved into a house with two other men from the special care home with whom he got along well. A staff member is present to support them. The men share many of the responsibilities for maintaining their house. Raymond gets out in the community on a regular basis. He is usually tired at the end of the day – he works in a local pallet making business. He is the only person with a handicap working there.

The citizens of the county where Raymond Langlois lives, formed an organization to support him and the other people from the special care home. There are now 29 people being supported in their homes because a second special care home closed. Half of them live in households of three people with handicaps like Raymond's but the rest live either in two-person households or with a family or a non-handicapped housemate.

These stories are being repeated across Canada by concerned communities. The situation in northwest Quebec was created by the determined efforts of an agency that wanted to redirect its efforts from institutional care to community living. The developments in Winnipeg were fostered by the joint actions of the local association working on behalf of people with handicaps and families, and aided considerably by the involvement of the members of churches. The changes which occurred in rural New Brunswick came about because a number of concerned citizens from many walks of life wanted something better for their fellow citizens.

**pseudonym*

As we look at the numerous examples of communities which are attempting to create decent homes for people, homes which respect their rights and encourage their involvement, a number of common features emerge. You can help to ensure that such features are part of the lives of the adults with a mental handicap in your community.

Common features of successful community living arrangements

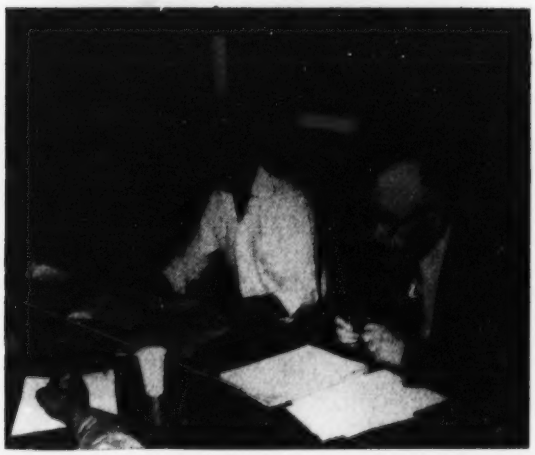
Underlying any effort at community living arrangements is commitment at a number of levels – thinking about where people live as homes and places of shelter, companionship and relationship; and designing and funding homes, what goes on in them, and who lives in them in response to the strengths and needs of the individual.

- First and foremost, attempts are made to reunite individuals with their families, or to keep them united with their families. This may involve the individual returning to the family home or ensuring that the family is actively involved in planning for the future and in the life of the individual. Families are provided with support in their homes – people to talk things over with and help solve problems, the opportunity to have a break once in a while, recruiting neighbours to help out, developing friendships with other adults who can involve the individual in the community.
- Whatever happens, every attempt is made to design the living arrangement in response to the individual, not to make the individual fit into the existing arrangement.
- When people live with others who are handicapped, the numbers of people sharing a household are kept small. More and more frequently, this means no more than three or four living together. When the needs of an individual are more challenging than the needs of others, because of *medical* or *behavioural* needs for instance, the number of others with a handicap is kept even smaller and/or the strengths of the others are such that they can assist the individual who needs more support.
- The emphasis is on people forming a household for themselves, so if staff or other non-handicapped people are present in the house, efforts are made to have them live in the house. These arrangements are often called "life sharing."
- A great deal of effort is put on developing relationships both in and out of the house with non-handicapped people who are not paid to be with the individual – neighbours, family members, friends of the staff, fellow workers, fellow parishioners, and so on.
- Every effort is made to encourage individuals with handicaps to choose the people with whom they live. In Winnipeg for instance, prospective new members of the housing co-operative may visit the house for a short time before a decision is made. People who already live in a house are involved in selecting new members of that household. When two people are not getting along and differences cannot be resolved, efforts are made to find a new home for one of them.
- More and more attention is being given to allowing adults with a mental handicap to have tenure in the houses in which they live. In Vancouver, individuals assisted by one agency are the tenants in the houses in which they live and they have leases. In Winnipeg, the members of the Prairie Housing Co-operative are members in full standing of the co-op and share ownership with other members. In communities across Canada, people are living in homes where they hold the mortgage. In two Atlantic communities, for instance, individuals have inherited the homes in which they live. In another Atlantic community, local associations are in the process of turning over the ownership of their "group homes" to the individuals who live in them.
- A firm commitment is made to solve any problems which may arise in the home, rather than forcing individuals to leave their homes. This means that people with challenging behaviours, for instance, are supported to stay in their homes. Support people are brought in to help the family, the housemates or the staff deal with issues. Extra people are available to live in the home during times of crisis.
- Every effort is made to design a person's living environment so that, as the person learns new skills and becomes more self-reliant, it will not be necessary for the person to move in order to be more independent. The first step is to keep the number of people living in a house small. Other steps include reducing the amount of staff support provided to the individual or the household as the person becomes more self-reliant; or encouraging individuals in households who want to move to "their own place" to do so, and letting the one or two peo-

ple who remain do more for themselves (and not adding more people to the household).

- Careful attention is paid to ensuring the people with handicaps and the people with whom they live (family, housemates, staff) get relief and respite.

LEARNING AND WORKING



Adults in our society meet their responsibilities as citizens in many ways. As husbands and wives, parents and members of households, we all have responsibilities. Many of those responsibilities are met at home – caring for one another, keeping the house clean and in good repair, feeding ourselves, planning for the future, raising children, and so on.

To keep ourselves, our families and our households going, however, requires us to earn a wage. And to earn a wage, we usually have to learn a number of skills required to get and keep a job.

We also better ourselves and our community by continuing to learn as adults. We advance our careers by learning new skills and ideas. We improve our abilities to be involved in the life of the community by learning to communicate better, and sometimes this means learning to read and write in the first place. We feel better and more capable when we learn to fix a car, climb a mountain, invest our money, understand the politics of this country, and so on.

And like it or not, the places where we work and learn, as adults, bring us into contact with other people. We develop relationships with those people as colleagues, friends, fellow students, and sometimes husbands and wives.

Working and learning are essential. They meet many of our social and economic needs –

- for money
- for experiences
- for love and relationships
- for power and rights
- for respect
- for meaning in our lives
- for being seen as valued adults
- for continued growth and development
- for new ideas and skills.

For Canadian adults with a mental handicap, however, opportunities to work and learn are often only dreams.

The Manitoba survey we mentioned earlier also looked at what adults who were living in the community were doing for work. These figures do not include those adults who were in institutions.

Work Related Activities of Adults Living Outside of Institutions

No work position	46.9%
Independent work	4.1%
Sheltered work	38.4%
Other*	10.6%

*Other = "working in a residential setting while contributing to upkeep of the home."

(Fishbach and Hull, 1982)

The experiences of many communities across Canada are not significantly different from those described in the Manitoba study.

These findings would not be very disturbing if, as many still believe, there was evidence to suggest that adults with mental handicaps cannot work at all, or cannot work in regular businesses, or simply cannot work because there are no jobs.

These findings are disturbing because the facts are:

- Adults with a mental handicap, including severe and multiple handicaps, can work.

- Adults with a mental handicap, including severe and multiple handicaps, can work alongside non-handicapped people in regular businesses and places of employment.
- Adults with a mental handicap, including severe and multiple handicaps, can find work and keep jobs even when jobs are hard to find.
- The best place for adults with a mental handicap to learn a job is on the job in the very places where the work is done, not in artificial settings.
- The best jobs to train and support people are the real jobs which exist in the community, not artificial jobs or recreational activities.
- All of these things are possible, though some individuals require support to achieve them, including on-going support on the job for considerable lengths of time.

Right across Canada, people with handicaps, families and communities are discovering these facts are true. They are attempting to obtain at least two of the following three results for adults with a mental handicap:

- **Meaningful work** – means a task, job or part of a job which, if done by a non-handicapped person, would mean getting paid. Doing things that are and appear to most people to be work.
- **Integration** – means doing the work in places where the vast majority of the other people in that place (other workers or customers) are not handicapped.
- **Pay** – means doing the work for a wage that is at least geared to the production level of the person.

It is also true that right across Canada, most adults with mental handicap are not engaging in meaningful work, much less in integrated settings or for a fair wage.

There are a number of reasons for this state of affairs –

- **Expectations are low.** Many governments, agencies and families have been encouraged to think that adults with a mental handicap either cannot work at all or require intensive and extensive training in sheltered environments (developmental centres, pre-vocational programs and sheltered workshops) before they can work.
- **Services are simply not available in many communities.** A study found that there are only 493 specialized vocational centres across Canada which serve 25,000 people with disabilities, 70 percent of whom have a mental handicap. More than two thirds of these centres are located outside of urban areas, that is, outside of major population centres. (Canadian Council of Rehabilitation Workshops, 1983.) We do not have good information on the number of services which actually support people to find and keep a job, but we do know they are scarce.
- **Generally, the services that do exist only train people for work, they do not find them work or help them keep a job.** Most sheltered workshop programs attempt to train people in "pre-vocational" and "vocational skills." When the individual is considered to be ready for a job then that person may be assisted to actually find a job. There are two problems here. First, adults with mental handicaps have trouble learning and generalizing what they have learned from one setting to another. Training in artificial settings (settings which are not like real work settings) and learning to do things which are not the real things that people do in these settings, therefore, does not work well. Second, people simply do not leave sheltered workshops for employment very often.
- **There are no reliable, systematic programs to fund and support efforts by communities to help adults with a mental handicap to find and retain meaningful work in integrated settings for a fair wage.** Federal and provincial programs in vocational services and employment are, on the whole, designed to rehabilitate and train people to the point where they can find their own jobs. The problem is that many adults with a mental handicap need something different – on-the-job training plus on-going support. Where "job placement" programs do exist, they frequently cannot provide the on-going support a person needs to do the job. Training is not the issue. We know how to train people on the job, and there are ways to fund such training. The issue is that once training is over, a number of people still need on-going support. (British Columbians for Mentally Handicapped People, 1985).

- **Schools rarely prepare young people for the world of work.** Unfortunately, most school programs for young people with mental handicaps are not designed to think about and experience work. Non-handicapped students are routinely provided with a number of opportunities – work experience programs, encouragement to do volunteer work, summer and after-school jobs, discussions with guidance counsellors and others about future job prospects, technical and career courses in school, co-operative programs outside school, career days and encouragement to go to community college or university. These experiences and opportunities are routinely denied young people with a mental handicap.

Adult education is for everyone

There has been much talk lately about the literacy (or illiteracy) problem in Canada. Studies show that up to one million Canadians cannot read this sentence. Some of those Canadians have been labelled as being "mentally handicapped" at some point in their lives. Having fallen through the cracks of the educational system, they have not been supported to learn a skill that is deemed essential to modern living.

Many communities throughout Canada are now recognizing this problem and are taking action to help people participate in everyday life by learning a skill that most of us take for granted.

Literacy programs, often staffed by volunteer tutors from the community, are teaching people such basics as banking, filling out job application forms and reading street signs.

Frontier College is the oldest adult learning institution in Canada. It began when this country was a new frontier and labourer-teachers were out working alongside and teaching people in remote communities.

Now the literacy programs have moved into the city cores where people with fewer opportunities often congregate. One such program associated with Frontier College is ***Beat the Street.*** *The program's founders are both people who at one time could not read themselves, but are now out there teaching "street people" or people who have fallen through the cracks of the educational system. It is a self-help group* ***par excellence*** *because it goes to where the people are and teaches them what they want to know.*

A typical lesson may involve Tracy Lequyere or Rick Parsons, the founders, walking down a busy street helping people read names of streets, warning signs, licence plates or whatever else comes their way.

Lequyere says now that he has been through the "nightmare", helped others learn to read, and established the program, he is now a full-time fundraiser. ***Beat the Street*** *organizers and volunteers plan to expand the program across Canada with an all-out fundraising drive.*

People can learn and work in the community – we can help them to do so

Within the living memory of many families and adults with a metal handicap, there were only two real options available in most communities in Canada – staying at home during the day doing very little, or finding a job on your own. For what may be the majority of adults with a mental handicap, this may still be the case.

There are, however, numerous examples of families and communities who have developed new ideas and put them into practice. Some have rediscovered old ideas that apply to most other people in communities, and they apply them to people with a mental handicap.

Some old ideas discovered

- Young people start thinking about what they want to do for a living when people ask, "What do you want to be when you grow up?" Even those of us who are older think about our options when someone asks, "what do you want to do next?" People with a mental handicap are

rarely asked such questions. They, and their families and teachers and friends, are starting to ask *and* take the answers seriously.

- A lot of us get an idea of what we want to do, and what we can do, by trying different things out - working for Aunt Marie at her office on the weekend, volunteering at the hospital, helping a brother build a treehouse or a sister fix the car, getting a summer job and talking to our friends and relations about what they do for a living. Families, handicapped people, teachers, agencies and others are starting to give people with mental handicaps, both young and old, the chance to try things out.
- Many of us get our first jobs and often others after that because of who we know rather that what we know - friends, relations, business people in our community, people at church, business associates who hear about a job opening, people we play hockey with and many others are all part of an informal network of contacts that puts us in touch with people with jobs. People with handicaps, families and professionals are increasingly using who they know to get that first chance, or to find out about the next change.
- Many of us learn what we need to know to get a better job by getting our foot in the door and working our way up the ladder. People with a mental handicap who are given an opportunity to start with a business, even if it is only for training, often end up staying in that business. The least that happens is they develop a reputation (or more formally, a résumé which will serve them well).
- Many of us do our work well or learn new skills because we rely on the support of our fellow workers. For a long time, staff have been hired in vocational services to teach people to do work that the staff themselves do not know how to do. They are human services professionals not woodworkers, or assemblers, or janitors, or dishwashers. Nevertheless, we are discovering two things. First, the staff of vocational agencies can learn to do a wide range of jobs and then teach those jobs to people with handicaps. Second, the best people to teach someone to do a job are often those who do that job for a living. Many people who work in regular business are more than willing to "help a fellow out" so ongoing support is not always needed from somebody outside the business (for example, from an agency).
- Many jobs require a number of people working together, each with a specific task which they do well. We have learned that small numbers of people with mental handicaps can work together to get one job done. Sometimes this means two or three people working together to get a job done that another person might do alone. The people working together get paid for the job and divide the wage among them. Other times this simply means having a person who is more able working alongside a person who is less able to get the job done. The job may be done slower, but it will be done nonetheless.
- There are many jobs that have a high turnover rate. They often require few skills which means that employers are always looking for someone to come in. These are often the jobs that many of us get when we are young and just trying to earn some money. We have learned that employers respond positively to the idea of such jobs being filled by people who will stay around. The employer gets the job done, saves time that would have been spent always looking for replacements, and saves money because the worker is not always in training.
- Sometimes, when work is hard to come by, the only answer is to start a business of your own, or in partnership with other people. Federal and provincial governments have funds and programs (economic development, co-operative development, job creation and so on) that help people start new businesses. We have learned that these same programs can be used to start businesses that hire people with handicaps. There are other people looking for work who are willing to enter into partnership with people with mental handicaps to start such businesses.

Some new things we have had to learn

- People with mental handicaps learn job-related skills and appropriate behaviours best when they are in the places where those skills will be used and are surrounded by people who expect appropriate behaviour and are models of it.
- Employers are willing to give people with mental handicaps a chance. They are more willing when agencies make and deliver a number of promises: support will be provided on the job, the job wil be done and problems will be solved.
- Many adults with a mental handicap find that meaningful work in integrated settings is initially more important than getting a decent wage. This "honeymoon" period, however, may not last more than a few months. People discover they can do the work. They enjoy being ac-

cepted for the work they do. They resent not being paid for it.

- In many cases, the "behaviour problems" which are evident in protected and segregated settings disappear or significantly lessen when the individual with the challenging behaviour is surrounded by people who expect appropriate behaviours and is placed in an environment where inappropriate behaviour is not rewarded.

Across Canada, there are many adults who are involved in gainful employment or in integrated programs which are skills and trades-oriented.

The following describes a videotape sequence that was made to see what kinds of changes are possible when a person is surrounded by a positive environment. The first scene is a simulated sheltered workshop environment. Bob Tanchuk is sitting at a table with some machine parts that need sorting. For three minutes we watch him do almost everything except sort the parts. He fidgets, he curls up. He bites his hand. He looks around. For a few seconds at a time, he sorts the parts. He looks and acts "retarded." He has a behaviour problem.*

The second scene is in the kitchen of a restaurant. Bob is standing at the dishwashing counter. He is busy sorting and scraping dishes. He talks to fellow workers as they pass by. He attends to the task at hand. He does not fidget, curl up, look around, or bite himself. Bob looks and acts like a dishwasher. He is a productive and contributing worker.

The first scene was taped Monday morning. The second scene was taped the afternoon of the same day. Although there are no such dramatic changes in people made on a regular basis, it is important to recognize that the environment is a powerful part of the conditions which either prevent Bob Tanchuk from being a citizen or promote his participation and contribution.

**pseudonym*

In Leeds and Grenville in southeastern Ontario, a group of parents and a voluntary organization decided to do something to help young people with a mental handicap in that area to get jobs. First, the parents were interested in having their sons and daughters enter the world of work in the community, not a sheltered workshop. Second, very little was being done in the schools to prepare the young people for work.

*The first step was a summer employment project. The project found work for five teenagers and formed a business - **Students at Work.** The business employed nine teenagers who are not handicapped and nine teenagers with handicaps. These university and high school students were paired up into teams which did short-term contracts over the summer such as painting garages, tarring driveways, cutting grass, spring cleaning, moving and stacking wood, cleaning windows, opening up and closing cottages and so on. The price for the job was negotiated with the homeowner and the wage was paid to the teenagers with handicaps. The second member of each team was paid through a grant which supported the project.*

The Leeds and Grenville County Board of Education administered the grant from Canada Employment and Immigration.

Through this project, 15 teenagers with handicaps worked. There were no admissions criteria - anybody who came received support. (Cartan, 1985).

For several years Community Living Mississauga has been supporting adults to find work, train them on the job, and support them to integrate on the job. The program, Community Vocational Alternatives (CVA) is one exciting new option of how people with handicaps can be supported to participate effectively in the community alongside non-handicapped people. (Sandys, 1985).

The program was evaluated in 1984 (Kappel, Howe, Hutchison, Larking, 1985). During that evaluation, discussions were held with staff, employers, families and the adults involved.

A fellow worker said:

- *It didn't take her long to settle into the job. On the first day she knew the names of six co-workers and soon found out the names of all the rest. I took her to lunch the first few days, then suggested that she go on her own.*

Some employers said:

- *Richard is great for us. He's just who we wanted. He takes an interest in the whole business and wants to keep the place clean.*
- *This is a family business, and he's just like a member of the extended family.*
- *I had experience with another program at another store. Three handicapped people just showed up one day without notice. They were hassled by the customers. We want to stay away from that image. CVA promised we would get someone who wanted to be involved in the retail business. They kept their promise... We're real happy with his progress. There's no way somebody's going to say he can't be part of the (store) hockey team... When he started he couldn't stock one aisle properly. Now he maintains the whole section.*

Some parents said:

- *This is a good project. He's a lot happier working than he was in the workshop. The only problem is getting out with the average person. He wants to live like the average person. He goes to the games, gets a couple of beers, goes out with the guys. The problem is, he's not getting paid so he doesn't have the money to pay for the beer or buy a round.*

And workers with a handicap said:

- *I used to sit a lot at the workshop. It's better here. I'm always busy. Never sit down.*
- *The workshop was more fun. The hospital means harder work. I like to work hard.*
- *I really got tired of making knife blocks at the workshop. It's better here. It's cleaner and there is more variety.*
- *I like my job. I'm learning a lot. Everybody is friendly and we get along. I'm meeting new people and customers.*
- *I'd rather get paid... I've learned what to look for in a good company.*
- *I like the job. I should be paid more. It keeps me occupied, my mind.*
- *I'd like to get an outside job, make my own money and get my own place. Sometimes there is not enough work. I feel better now.*

Not everybody works in competitive employment outside their homes. Some young adults would prefer to further their education or at least enjoy some of the benefits of student life for a while longer. In Winnipeg, Manitoba, the parents of four young women, all of whom have very challenging needs, decided they wanted their daughters to get some of the benefits of college life. In the February 22, 1985 issue of the Red River Community College newspaper, the results of their efforts were described.

> *Project Inclusion integrates severely handicapped people into the college community. Four women, all in their twenties and with various physical and intellectual limitations, are taking part in college activities. These range from classroom lectures to sports events and beer bashes. The emphasis is not on formal training, but rather on improving the quality of life of handicapped persons through interaction and experience with non-handicapped peers.*

Each of the young women has an aide (funded through Canada Works) who assists in implementing the daily schedule which is different for each woman. The students are not segregated in their own classroom, rather they participate freely in college events and opportunities. One of the young women is Catherine Schaefer who is well known to many because of her mother's book, "Does She Know She's There?" (Schaefer, 1982).

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*pseudonym

LIVING TOGETHER, MARRIAGE AND PARENTHOOD

Just as we all want to grow up, have a place of our own and get a job, many of us eventually want to get married and have children. We consider it our right to do so whether or not we actually do it.

People with handicaps have traditionally been denied this right and have been separated from persons of the opposite sex and often sterilized without their consent.

Now that more people are remaining in or returning to communities they are more likely to have the opportunity to develop close relationships with others with whom they may want to share their life. Just like any other couple, they may or may not be successful in maintaining their relationship and making it permanent. And, just like any other couple, they can be supported to learn what it means to share your life with another person. This support may come from friends, families or counsellors. It may involve learning about sexuality, birth control, money management or just everyday life.

Some people who do decide to share their lives may decide to have children. This is also a right that must be respected just as it would be for any other non-handicapped adults. And just like other adults, people with handicaps may require some support to raise and care for their children appropriately.

In addition to the support of friends and family, there are programs aimed at parents with handicaps that can help people in their own homes or in community centres. Studies have shown that, with supports, parents can significantly improve interactions with their children, can make their homes more conducive to learning and can learn to teach their children developmental activities. (Parks, 1984).

GETTING OLDER

After spending most of our adult years working, many of us look forward to retirement and enjoying the life that we have built. Because of advances in medical care and in the quality of various services we receive, most of us will live longer to benefit from our life's work.

People with a mental handicap are no different. In fact, the principles that are guiding more recent thinking about aging in our society are equally applicable to older persons with a mental handicap.

A recent discussion paper from the National Advisory Council on Aging outlines some of these principles:

- The primary interest of seniors is to continue to live autonomously in the community and preferably in their own home.
- We believe in the autonomy of the person and that people should have the opportunity to choose when and how decisions affecting their lives and health are made.
- We believe in the importance of the family since it is desirable for family members to help one another when help is needed.
- We believe that people, regardless of age or ability, should be able to maintain the maximum degree of independence in their lives.
- We believe in the importance of leading productive lives contributing to the betterment of society.
- We believe the benefits of society should be shared to provide equitable services to all Canadians.
- We believe in the individuality of the person. People differ from one another, and these differences need to be taken into account when services are provided.

- Community support services refer to a co-ordinated and integrated range of services designed to help people lives as independently as possible in the community enabling people to continue to be responsible for all aspects of their lives within their capacity to do so, thereby promoting a healthy physical, mental, social and emotional involvement with family, neighbourhood and community.
- The most important continuing support available to a person in need is the family, followed by friends and neighbours. Both the individual and the family must be supported by the community and in turn, society has an obligation to ensure that community support is in place. (National Advisory Council on Aging, 1986).

The perspective is similar, as are the issues. The National Advisory Council notes that the rate of institutionalization, that is, that rate at which senior citizens are separated from their communities, in Canada is among the highest in the world. For all citizens, including those with a mental handicap, growing old should not mean being set aside or set apart.

Conclusion

Citizenship is the key concept when we aim to make a difference in the lives of adults with a mental handicap. It underpins the legitimate and valued roles in which adults are expected to be involved. Our fundamental rights and freedoms as adults place limits on what others can do to us and for us. They also place an obligation on us to participate and contribute to the life of our community. To deny rights and freedoms, is to handicap citizens. To promote rights and freedoms, is to promote lives of quality.

For babies and children, the major concern is to prevent the acquisition of intellectual impairment. If that is not possible, then the concern is to prevent further handicap (see Preface). For adults, however, the prevention of further handicap is the major concern. Such prevention can take the form of:

- Ensuring that the person's abilities, not disabilities, are the basis for future planning.
- Ensuring that social and physical environments (expectations, attitudes, ways of doing things and physical structures) are positive environments; that they do not stand in the way of adults with mental handicaps; and that they do promote the participation and contribution of adults.
- Ensuring that conditions and practices do not lead to the further acquisition of impairments and disabilities; that what we do, the places we create and our expectations do good rather than harm.
- Many of our current practices and the conditions we have created work against adults with mental handicaps taking their place in and mak-

ing their contributions to the community. The prevention agenda is long and challenging.

- We are developing new ways of doing things in communities across the country which demonstrate we can not only prevent handicapping conditions, but also promote lives of quality.

To love and to be loved, to respect and to be respected, to receive and to give support, to depend on others and to have others depend on you, to be young and to grow old with dignity and to have a sense of having contributed – these are the cornerstones of adult life. These are the important topics of this volume of Making a Difference. The challenge is not to create better services, though better services are needed. The challenge is to create better communities of support, of self-reliance and mutual reliance, so that our fellow citizens with a mental handicap can take their rightful place in the community – as respected, participating and contributing citizens.

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